Original Article

The MyPath Pain Pathway: Developing a Digital Patient-Centred Care Pathway for Cancer Pain

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Abstract

Context. Cancer pain affects up to 45% of patients, with more than 30% experiencing moderate to severe pain. Despite established guidelines, over 40% of patients receive inadequate pain management, severely impacting their quality of life. While effective pain assessment is essential, a standardized approach is lacking in both research and clinical practice.

Objectives. MyPath, a European Union-funded project, aims to implement a patient-centered care (PCC) approach across nine European cancer centers by systematically assessing and managing common symptoms and psychosocial issues to improve PCC for cancer patients. The aim of the present article is to describe the development of the clinical content for the MyPath Pain Care Pathway (PCP), based on patient reported outcomes (PROs) and clinical assessment, designed to offer standardized multidimensional pain management.

Methods. Between September 2022 and August 2024, an international, multidisciplinary steering group developed a systematic method for assessing and diagnosing cancer pain using evidence-based guidelines.

Results. The MyPath PCP pain assessment includes five key components: pain etiology, location, intensity, flares, and treatment (including relief and dose-limiting side effects), in line with the ICD-11 classification. Data will be gathered through digitalized PROs and clinical consultation in the MyPath's digital solution, which will suggest individualized pain management strategies. The first version of the tool will be implemented in 2025, with further adaptations based on feedback from patients, caregivers, and healthcare professionals.

Conclusions. The MyPath PCP represents a digital standardized pain assessment approach to improve the quality of pain management for cancer patients across clinical settings. J Pain Symptom Manage 2025;70:592–601. *© 2025 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)*

Key Words

CANCER pain, patient-centered care, care pathways, personalized care, palliative care

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Key Message

The MyPath PCP offers a digital comprehensive and standardized assessment approach designed to enhance tailored pain management and improve the standard of care in routine clinical settings.

Introduction

Patients with cancer often endure a combination of physical, psychological, existential, and social challenges, many of which can be undetected or addressed inadequately, leading to unnecessary suffering. MyPath[1,2] is a European Union (EU)-funded project under the Horizon Europe call and Europe's Beating Cancer plan that aims to implement a systematic approach to identify individual needs and appropriate management options to help achieving patient-centred care (PCC).[3] MyPath focuses on addressing common symptoms, including pain, nutrition, and emotional distress, through the development of patient-centred care pathways (PCCPs). These standardised care pathways, supported by health information technology, also called digital patient-centred care pathways (dPCCPs), aim to ensure that patient care is delivered systematically according to patients' needs.

Pain is one of the most common and feared symptoms in patients with cancer,[4] with an overall estimated prevalence of around 45% and 30% of patients reporting moderate to severe pain. Unfortunately, cancer pain remains an unmet need,[5] impacting significantly on quality of life, physical functioning and psychosocial dimensions.[6-8]

Despite the existence of numerous guidelines[9-12] designed to optimize cancer pain assessment and management, more than 40% of patients[5] still experience undertreatment, indicating a substantial gap between knowledge and practice. Barriers such as limited time during consultations, inadequate pain assessment, and reluctance to prescribe opioids, the mainstay drugs used in treating moderate to severe pain caused by advanced cancer,[9-12] contribute to this issue.[13,14] Additionally, patient-related barriers, such as hesitancy in reporting pain or fear of side effects, complicate the implementation of effective pain management strategies.[15,16] To all the above is added also the inter-individual variability among both healthcare providers (HCP) and patients.[17,18] It also remains unclear if pain management guideline implementation strategies can improve pain-related outcomes for this population of patients, and which are the best strategies and resources needed to achieve this goal, although several attempts have been reported in literature.[19-21]

The complexity of cancer pain calls for a tailored, mechanism-based approach to treatment and effective pain management requires a detailed assessment and an individualized treatment plan, based on the underlying causes and the specific needs of the patient.[22-27] However, many clinicians, including oncologists, face challenges in adopting this approach, often due to a lack of training or resources.[28] Given the high variability in pain presentation and the differences in knowledge among HCP, a standardized, practical assessment that incorporates all relevant patient-reported data could help optimize treatment and facilitate guidelines' implementation and a more effective pain management.[5,29,30]

Self-reporting of pain is an essential component of individualized care, considering its multidimensionality and subjective nature.[31] To this end, patient-reported outcomes (PROs) and patient-reported experiences (PREs) have been developed and validated to assess and quantify patients' pain levels and related symptoms.[32] PROs have been shown to improve symptom management and even survival outcomes,[28,33] but their full potential has yet to be realized due to inconsistent implementation across clinical settings. Moreover, while digital collection of PROs is feasible[34,35] and can provide a platform for continuous assessment and facilitate access to HCP to this data,[36] the integration of this data into clinical practice remains limited.

To address these gaps, there is a clear need for a new approach to the systematic implementation of evidence-based cancer pain assessment and management. The MyPath project seeks to bridge this gap by developing and implementing a PCCP for pain, the MyPath Pain Care Pathway (PCP), which can be used by both pain specialists and nonspecialist clinicians as an integrated part of the MyPath digital solution.

This paper outlines the development process of the first version of the MyPath PCP.

Methods

MyPath overview and structure of the digital solution

In September 2022, MyPath initiated a two-year project period (September 2022 − August 2024) focused on the design and development of the structure and scientific content of the MyPath PCP. As an implementation project, the keystone of MyPath has been its agile and iterative methodology that envisions continuous internal and external diverse stakeholders' involvement in the co-creation process to ensure that the result is scientifically sound and aligned with clinical practice.[37]

The agreed structure of MyPath begins with the onboarding of the patient into the digital solution, followed by a patient-centred assessment and management plan, which in the specific case of PCP would be as follows:

- PCP Assessment: composed by the *PROs and Clinical Consultation; PROs* will be collected using a digital format based on Eir.[38] Patients can fill in the assessment at home or at the hospital. This information will be available for HCP before the consultation and guide the clinicians to gather additional data from the *clinical consultation*. The combination of these data will result in a Pain Diagnosis.
- PCP management plan: based on the Pain Diagnosis, the solution will suggest different treatment options tailored to the individual patient's needs and preferences. Considering this information, the clinician will ultimately establish the Treatment Plan, which will be discussed and agreed on with the patient and caregivers, ensuring shared decision making. The next step of the management plan is the Follow Up either digitally or physical. The Follow-Up can be according to plan or as needed.

The other pathways developed in MyPath including nutrition (e.g. nutrition - further described in "Practical cancer nutrition, from guidelines to clinical practice: a digital solution to patient-centred care", accepted in ESMO open, pending publication), emotional distress, and social issues, follow a similar structure.

Multidisciplinary steering group for pain

The international multidisciplinary steering group for the development of the PCP was assembled in December 2022. The steering group comprised medical oncologists, palliative care and pain clinicians, neurologist, and researchers from five countries. It included members from the International Association for the Study of Pain (IASP) and authors of international consensus guidelines for the European Society for Medical Oncology (ESMO) and European Association for Palliative Care (EAPC), and authors of leading publications and reviews focused on pain assessment and management.[9,10] Moreover, the group included a scientific lead and a coordinator, who acted as facilitators in the development process, discussions, and guaranteed that the PCP was based upon the best evidence available.

Development of the pain care pathway content

The iterative process for the development of the PCP content entailed different steps. The starting point was a comprehensive review of available international guidelines and recommendations for pain assessment and treatment, focusing on relevant original articles and systematic reviews. The involvement of some members of the group in the writing of these publications at the EU level facilitated familiarity with the material and guaranteed the alignment of the classification system with current practices and recommendations. Validated tools for both PRO and clinical pain assessment were identified and reviewed. Out of the validated tools, items were selected, and adapted to the digital format when needed, to facilitate the applicability in routine clinical practice; also building on the pre-existing EirV3 system,[32] a computer-based platform for patient-reported outcome measures in cancer, which has undergone face validity, usability testing and demonstrated feasibility. To address language and socio-cultural differences across the participating centres, a dedicated working group supervised translation locally and contributed by using validated translations or forward-backward translation when the later were missing. Testing with patients and healthcare professionals was also performed.

The main principle was to compile a feasible and easily applicable assessment that would guide the appropriate diagnosis and lead to the initiation of an evidence-based pain management in clinical practice. The following steps entailed the identification of those items that would be collected as PROs providing an initial assessment of pain, and those that should be inputted during the clinical consultation with the HCPs.

Different patient cases examples were created to allow the illustration of how the classification could tailor the management recommendations for the individual patients. This proved also useful in illustrating the structure and the development of the PCP to clinicians involved in routine care of patients with cancer, allowing for the collection of relevant feedback and ensuring the feasibility of its application in the oncology clinical setting.

Throughout the development process, to enhance patient and clinician engagement, HCPs and patients have been actively involved in the development of content and its digital structure. Co-creation sessions have been held regularly throughout the development process with HCPs and iterative meetings and testing processes have been performed, to ensure that the proposed pathway aligns with clinical workflows and respects their expertise.

Results

Final Variables for the PCP Assessment and Pain Diagnosis

The agreed pain assessment of the PCP includes pain aetiology, location, intensity (at the time of the assessment), flares, pain treatment (Fig. 1).[9,10,24,25,39-45] When flares are present, the intensity of the episodes and triggers will be included. Moreover, for those patients already receiving pain treatment, the relief provided, and the presence of opioid-related side effects (for patients receiving opioids) completes the assessment.

	Pain classification and assessment tools				International guidelines	MyPath Pain Assessment	
	BPIsf	IASP	ECS-CP	ICD-11	ESMO, EAPC	PROs [a]	Clinical Consultation
Location	✓	✓			✓	✓	
Intensity	✓	✓			✓	✓	
Worst Pain	✓				✓	✓	
Pain Now	✓				✓	✓	
Flares		✓	✓		✓	✓	
Neuropathic descriptors			(✓)		✓	✓	
Aetiology		✓		✓	✓		✓
Pain treatment	✓				✓		✓
Pain relief	✓				✓		✓
Side effects					✓	✓	✓

Fig. 1. Selected variables for pain assessment and their use in international pain assessment tools and guidelines. BPIsf = brief pain inventory short form; EAPC = European Association for Palliative Care; ECS-CP = edmonton classification system-cancer pain; ESMO = European Society for Medical Oncology; IASP = International Association for the Study of Pain; ICD-11 = International Classification of Diseases version 11.

[a]Data collected before the consultation. Will be reviewed and confirmed by the clinician.

Data Retrieval

Fig. 2 summarises the content and flow of information that leads to the MyPath pain assessment, as follows:

PROs - Patient Assessment

Prior to a clinical consultation, patients will be prompted to complete a PROs assessment using the digital tool, that includes a section for symptoms screening. From the list of symptoms, patients will mark those that are or have been present during the last week. The software follows computer adaptive testing, thereby asking patients only relevant questions based on prior answers, mimicking normal clinical consultation.

Patients that mark having pain are asked to indicate the worst pain intensity during the last week (Numerical rating scale (NRS)[46] 0 − 10, 0 being no pain at all and 10 the worst pain imaginable) and those reporting pain intensity on a NRS ≥3 will continue with the full

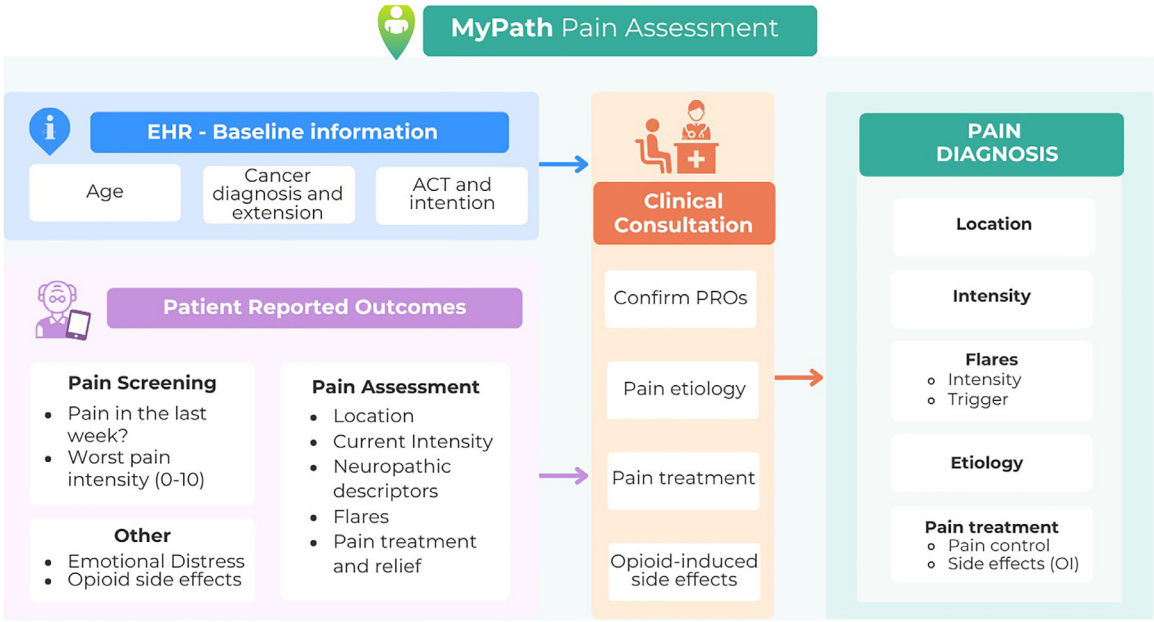

Fig. 2. MyPath pain assessment of the PCP. ACT = Anticancer Treatment; EHR = Electronic Health Records; OI = Opioid-Induced; PROs = Patient Reported Outcomes.

pain assessment. This will include the following: the location of the most painful area in the body map, the intensity in that location at the time of assessment, the characteristics/neuropathic descriptors of the pain (burning, cold, tingling, or feeling cold, sensitivity to touch, electric shock, numbness, strange sensation) the presence of pain flares, their intensity and triggers, and finally, patients will indicate the relief provided in the last 24 hours by pain treatment from 0 to 100% (0%= no relief, 100% = Complete relief), and if they deem the pain under control (Yes/No, categorical answer). Patients with more than one pain will have the opportunity to indicate so once the whole pain assessment of the most painful area takes place.

In addition to the specific questions related to pain assessment, patients will be screened for opioid-induced side effects. These will be included in the list of symptoms patients are screened for in PROs assessment. If the patient selects a specific symptom, they will continue indicating the intensity in a NRS scale from 0 to 10 (0 = absence of the symptom, worst intensity imaginable for that symptom). Moreover, patients will be assessed for existing emotional distress, and its cause.

Clinician Consultation − HCP Assessment

During the clinical consultation the HCP will review the data collected via the digitalized PROs. Based on these answers, and available information on cancer disease, available diagnostic test (CT scans, MRIs, etc.), and prior and current anticancer treatment, the clinician will indicate the etiology of the pain (cancer pain and involved tissues, postcancer treatment pain, noncancer pain) based on the classification system proposed by the ICD-11[24] . Additionally, current treatment used for pain management, pain control (confirmation of patient inputted data) and potential opioid-related and dose-limiting side effects will be assessed.

PCP Pain Diagnosis and Management Plan

Integration of the information coming from the digitalized PROs and clinical consultation will lead to a classification or a Pain Diagnosis based on the following variables: location, pain etiology, intensity, flares and treatment (relief and dose-limiting side effects), as follows:

Location

Location, as indicated by the patient on the electronic gender-neutral body map[47,48] that is codified for different anatomical body areas;

Pain Etiology

Based on the ICD-11 recommendations and pain syndromes[24,45] identified during the clinical assessment, pain will be classified as either: cancer pain, postcancer treatment pain, noncancer pain or unknown. For cancer pain, or pain due to tissue involvement by the cancer mass or its metastases, the type of tissue involved will be selected: soft, bone, nervous, visceral or a combination of more than one tissue. Similarly, for pain due to anticancer treatment the specific cause will be required as follows: due to chemotherapy, radiotherapy, postsurgical, due to targeted therapy, immunotherapy, other. If the etiology is unknown, the HCP will be prompted to review the clinical history and imaging or request further diagnostic test to determine the cause of pain.

Pain Intensity

The pain reported on a numerical rating scale from 0 to 10, at the time of assessment, will be used for classification purposes: for NRS 1-4 as mild, NRS 5-6 moderate and 7-10 severe pain.[49]

Pain Flares

Presence of flares will be evaluated using a dichotomous Yes/No answer, pain intensity of the flares will be evaluated using a NRS 0-10 and triggers (movement, coughing, defecation, urinating, swallowing, other, none) will be assessed.

Control With Pain Treatment

If the patient will be using pain medications at the time of the assessment, the classification will also provide information if pain is deemed controlled with the current medication, using a dichotomic Yes/no answer and the percentage of pain control using a scale from 0 to 100%. If any side effects related to pain medications are reported by the patients, the classification will provide information if these are dose-limiting side effects, based on the data reported by the HCP.

Based on the above, the MyPath PCP will recommend a management plan for pain treatment and prevention of eventual side effects (Treatment Plan) based on available guidelines and local clinical practice, and a Follow-up schedule. These suggestions will include references for starting doses, titration, contraindications, reassessment, and adjustment of specific drugs based on the guidelines. However, the clinicians will have the ultimate decision, and the initiation of the specific suggestions provided will depend highly on both HCPs and patients' preferences.

The treatment options that will be included in MyPath dPCCPs can be categorized into patient education resources, self-management advice, nonpharmacological interventions, pharmacological interventions, diagnostic procedures, and referrals to other clinicians. Patients' empowerment will be prioritized and education of the patient through educational material will be actuated as part of the dPCCP. Fig. 3 provides examples from the PCP for each of the categories.

Type of care option	User [b]	Description	Examples for pain
Patient educational resources [a]	Patient	Information regarding current diagnosis, FAQs, prescribed medication, etc.	Explanatory document on opioid use for pain
Self-management advice [a]	Patient	Interventions patients or informal caregivers can initiate to improve the current condition	Position changes, relaxation, rubbing...
Non-pharmacological interventions	Patient	Interventions or procedures the patient will receive and are usually (not always) applied/ delivered by a specialist	Physiotherapy, TENS
Pharmacological interventions	Patient	Any kind of treatment or interventions that require a prescription from a specialist	Initiation of WHO step 1 medication
Referrals to other clinicians	Clinician	Referrals to other clinicians	Referral to palliative care specialist
Diagnostic procedures	Clinician	Diagnostic procedures needed to complete the classification: questionnaires, blood testing, imaging	Review or order imaging for ascertaining pain aetiology

Fig. 3. Examples of treatment options suggested by the MyPath PCP. FAQ = frequently asked questions; TENS = transcutaneous electrical nerve stimulation.

[a]Written documents, infographics, video

[b]User represents the individual that will receive or act upon the care option

Once the clinician specifies the pain management, a follow-up plan will be established, which will entail both continuous monitoring via digitalized PROs and clinical consultations, when needed, according to some predefined time points and/or depending on patients' necessities.

Clinical Case Example

To illustrate the above, as part of the iterative process of developing the PCP, different scenarios of improvised clinical cases were developed. To simplify the practical understanding of the PCP, Fig. 4 shows the sources and flow of information that leads to the pain diagnosis and management plan when using the MyPath PCP.

Case vignette: The hypothesized case study refers to pain assessment in a 67-year-old male patient diagnosed with metastatic lung cancer with bone and lymph nodes metastases. He is currently undergoing anticancer treatment with immunotherapy with life-prolonging intention. He has an appointment at the cancer center for the administration of a new immunotherapy dose. He is currently experiencing pain in the lower back.

Local Configuration and Future Adaptation

The MyPath digital solution and the dPCCPs should be configurable, meaning that they can be adjusted to fit local needs and practice. Similarly, to ensure its implementation, the PCP will be further adapted to each cancer centre. Hospitals where MyPath will be introduced are being studied a priori through an implementation science model so that it will adapt to local practices, guidelines, and resources. This will entail further adaptations to the local language and culture, but also adjustments based on local resources, practices, and guidelines. In 2025, MyPath will begin the staggered implementation of the MyPath dPCCP in 9 cancer centres in Europe. The input and feedback collected from patients, caregivers and HCP during this period will lead to further modifications and adaptation of the current classification system to assure its implementation in cancer care.

Discussion

This article describes the development of the PCP clinical framework based on a comprehensive pain assessment, ensembled by a group of international collaborators, with the aim of improving and facilitating tailored pain management in patients with cancer in oncology through digital implementation.

While the relevance of good assessment and classification of pain is well recognised[26,27,43] and various classification systems have been developed,[24,50,51] there is no standardized classification system widely used in research and clinical settings for diagnosis purposes.[26] Additionally, most of these classification systems provide insufficient insights to guide the initiation or implementation of evidence-based pain management recommendations. The goal in the development of the classification system of MyPath was to provide an easy-to-use assessment that gathers sufficient data for the initiation and follow-ups of effective pain management.

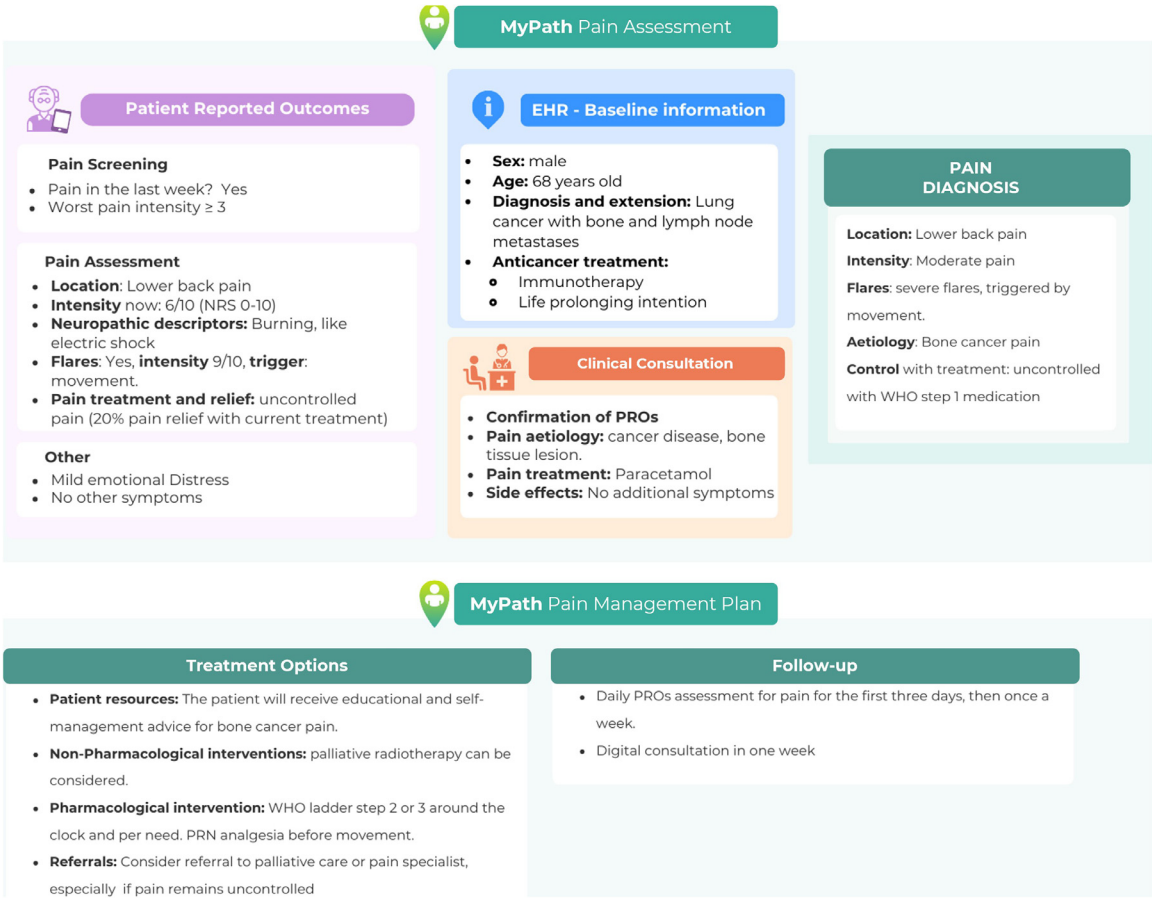

Fig. 4. Pain care pathway illustrated with a clinical case example. EHR = electronic health records; NRS = numerical rating scale; PROs = patient reported outcomes; WHO = World Health Organization.

The process of including or excluding several variables, relevant for the final diagnosis of pain, was a thorough one, which, as explained above, consisted in an iterative process based on the interaction among specialists in the area and clinicians involved in the everyday clinical practice from the different centres involved in the study consortium. All items were derived from already validated assessment tools (Fig. 1).

As part of this process, a practical assessment tool that could provide essential information without imposing a burden on patients or healthcare professionals was required. The use of a digital platform and adaptive testing helps to reduce this strain. Meanwhile, the iterative approach in selecting components for pain diagnosis ensures that only the most critical characteristics are evaluated.

While it is not possible to provide a one-fit-for-all solution, the final product had to be specific enough to guide clinical practice, but also flexible to adapt to the different clinical settings in different centres worldwide. Considering the differences in local guidelines implementation, cultures, and clinical practice routines in different countries, local adaptations of the proposed classification and care options will take place in the different centres to ensure they align with the local practices.

As part of this iterative process, several relevant dimensions for pain assessment, such as emotional distress and interference with daily function, are not explicitly covered in the PCP. This was done intentionally as the digital solution will include specific pathways evaluating this separately from the PCP, but the presence of emotional distress concomitant to pain, will lead to specific suggestions to ensure both dimensions are addressed, which will require a further refinement of the digital solution.

The strengths of the PCP include an assessment reliant on a "HCP (user)-developed" algorithm, developed in collaboration with an international experts' group from different centres. Moreover, the proposed classification system is focused on the minimal necessary numbers of variables for providing both an accurate pain diagnosis and recommendations on pain management, with the opportunity to tailor and improve pain management and QoL in oncological patients. The MyPath dPCCP as whole will not only assess pain and classify patients accordingly, but it will also suggest management options via a decision support module. However, the assessing clinician will

ultimately make the treatment decisions together with the patient. Algorithms will be available for any drugs the clinician decides to prescribe, and these algorithms will include the need to tailor dosages to patient status (age, frailty, kidney or liver function). In addition, the patient's cancer disease status will play a role in pain management in cancer survivors, patients with active cancer and patients receiving end-of-life care.

Some limitations need to be acknowledged. The data and PCP here presented refer to the results obtained so far and as mentioned above, modifications and/or adaptations might be needed throughout the process of implementation based on feedback from both patients and HCPs from the different centres. Further empirical testing and clinical validation will shed light on how we can improve the next versions of the digital MyPath system, based also on the feedback collected throughout the implementation phase of the study. This is true also for items included in the solution, which have been adapted and combined from existing tools. We acknowledge that this might influence their underlying psychometric structure, although efforts were made to preserve integrity throughout the development. As part of the implementation study, we will carefully evaluate cross-cultural psychometric properties and revise items and scales as needed, with subsequent versions of MyPath PCP to be published accordingly.

The development of the different pathways and classification systems, embedded in a digital solution, is just a fraction of the work put into MyPath. Implementation science will be key in the assessment of current practices, clinician involvement and co-creation, and support the necessary clinical steps and changes in the behaviour needed to achieve patient-centred care. Yet, there are still some common barriers which are characteristic of implementation studies and hence will need to be considered also in the present study. These include limitations related to the context of the study, which will require frequent adaptations to the solution, agreement of all key stakeholders, user-related limitations, but also infrastructure related limitations related to the adequacy of the necessary hardware/s and internet connectivity.[52,53] Additionally, the use of digital information systems is often related to changes in workflow, which could also lead to work disruption, influencing implementation and satisfaction of the end users.[54,55] Deep stakeholder engagement with involvement from local, national and international leaders has been performed from the early stages of the study, before implementation, to ensure its success. Both qualitative and quantitative assessments will be conducted throughout the implementation to ensure that the final product aligns with needs and can be adopted and scalable widely. Additionally, tutorials and training will be provided to ensure that the MyPath and its PCCPs can be easily adopted in different settings. These efforts align well with social and healthcare needs in a landscape of constant change and digitalization for better and more efficient care.

Future evaluation of the pathway will allow to better understand its impact on pain assessment and management in routine care but also overall patient satisfaction, usability, clinician adoption, and integration into clinical workflows.

Conclusion

The PCP in MyPath provides a framework for a stepwise digital pain assessment system linked with evidence-based treatment options to improve pain management in patients with cancer. The development of the MyPath PCP marks an important step in improving the quality and consistency of pain management across diverse healthcare settings. The ongoing adaptation of the pathway in nine cancer centres will ensure its relevance and effectiveness, making it a dynamic tool for implementation across Europe and beyond.

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